

Chapter 5

**Making Decisions for
Those With Dementia**

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Making Decisions for Those With Dementia

Carolyn, 63, is in her second year in a nursing home. She has Alzheimer's disease and is no longer cognizant of her family or her surroundings. She is still remembered and loved by family members, who visit her regularly to check on her care and to assure themselves that she is nursed properly and made comfortable. The family is aware of the progression of the disease and has requested that the nursing home withhold life-sustaining measures when the time for such action arrives. When Carolyn contracts pneumonia and it becomes serious, the nursing home is faced with the decision to withhold treatment and balks. The nursing staff feels that death from pneumonia is painful and difficult; Carolyn contracted it accidentally and withholding treatment does not seem either right or natural. They call the local hospital and transfer Carolyn to it; there she begins to receive the treatment the nursing home was asked to withhold. The family is then faced with a new dilemma in carrying out what they feel to be a humane decision. They must again appeal to the medical staff, this time to withdraw treatment that has been started on Carolyn. Withdrawal of treatment, they find, is more difficult to obtain, and the legal process with which they are faced is becoming increasingly more complex. The State Carolyn lives in has family consent provisions, but no clear-cut guidelines on the authority to make termination of treatment requests.

Robert is in the early stages of Alzheimer's disease. Even though he experiences fewer and fewer moments of lucidity, he knows what illness he has and what will eventually happen to his mind and his body. He talks about it with his wife and children, expressing his horror at being kept alive beyond his ability to be aware of life. Robert also has a chronic kidney condition that worsens and finally causes his hospitalization. An examination results in the medical conclusion that Robert must be operated on in order to save his life from imminent renal failure. Robert is told about the medical decision, but he refuses to give permission for the operation. The specialists, however, appeal to his wife and children for permission to

operate; they also refuse, stating that they feel Robert has made a rational decision. The surgeons disagree. They are bound by oath and tradition to save Robert's life and they ponder the consequences of going ahead with the operation, declaring Robert incompetent to make the choice. Robert has executed a durable power of attorney, naming his wife attorney-in-fact, but laws in his State of residence are unclear as to whether attorneys-in-fact can make critical care decisions.

Jane, a 73-year-old, cheerful, vigorous female in the early stages of a progressive dementia, falls ill and is bedridden in her apartment. During her illness, her sister attempts to shop and cook for her, but Jane's condition deteriorates and she becomes incoherent and incontinent. Her sister immediately petitions for, and is granted guardianship over Jane's person and property. With Jane's condition steadily worsening, her sister also arranges for her entry into the hospital. The hospital tells her sister that Jane will have to undergo major surgery. Her sister requests that the surgery not be performed, in accordance with wishes stated by Jane at an earlier time. The hospital, pointing out that Jane has no formal advance directive for nontreatment, and that the State laws are unclear about guardians having the authority to make critical care decisions, goes ahead with the surgery. Jane survives surgery but shortly thereafter goes into an irreversible coma. When medically appropriate, arrangements are made for nursing home care. With her nutrition and hydration provided by tubes running into her nose and stomach, Jane may live for many years in this fashion (14).

These sketches bring painful clarity to several legal and practical problems that arise when individuals with a progressive dementia are no longer capable of making decisions regarding their own health and welfare. Each case involves a "surrogate decisionmaker" or someone who is empowered to make certain decisions on behalf of another person considered incompetent to make the judgment personally. This chapter will exam-

ine some of the issues surrounding surrogate decisionmaking, particularly as it relates to the medical care of incompetent individuals.

As part of this assessment, OTA commissioned papers entitled “Surrogate Decisionmaking for Elderly Individuals Who Are Incompetent or of Questionable Competence,” and “Withholding and Withdrawing of Life-Sustaining Treatment for Elderly Incompetent Patients: A Review of Court Decisions and Legislative Approaches.” These papers were discussed at an OTA workshop in Washington, DC, September 23, 1985. As a result of the workshop, OTA commissioned an additional paper on “Legal Perceptions and Medical Decisionmaking.” These three papers, which contain an extensive analysis of the surrogate decisionmaking questions discussed in this chapter, will be published in 1987 by Milbank Memorial Fund as a supplement of *The Milbank Quarterly* and by OTA (see contract appendix for more information).

Surrogate decisionmakers are responsible for making decisions about an individual's health care,

lifestyle, and estate. The limits on and types of decisions made depend on the type of surrogate and manner of appointment, as constrained by the laws of the State in which the incompetent individual resides.

Surrogates may be chosen by an individual before he or she becomes incompetent, appointed by a judge after an individual is incompetent, or identified by laws in certain States that automatically grant family members surrogate decisionmaking powers. Surrogates may have detailed decisionmaking instructions the individual wrote before becoming incompetent, or they may have no instructions whatsoever. Although circumstances may mandate the need for a surrogate decisionmaker, the designation of one calls more into question than the single decision needed in response to a specific problem. The determination of incompetence sets into motion an exploration of such fundamental issues as an individual's autonomy and a surrogate's ability to make decisions for another human being.

DETERMINING COMPETENCE

American society is based on the recognition of individual liberty. Competent individuals have the common law fundamental right to control their property, manage their personal affairs, and give or withhold consent for any bodily invasions such as medical treatment.

As early as 1905, an Illinois court held that “under a free government at least, the free citizen's first and greatest right which underlies all others—the right to the inviolability of his person, in other words, his right to himself—is the subject of universal acquiescence, and this right necessarily forbids a physician . . . to violate without permission the bodily integrity of the patient” (54). This concept of bodily integrity has been defined by the courts to provide that, for a patient's consent to be valid, the physician must provide him or her with enough information about the proposed treatment that the patient can give an “informed consent” (12).

As clear-cut as these basic rights appear, they pertain only to persons assumed competent to make decisions. Questions surrounding a possibly incompetent individual remain: What makes a person competent in the first place? What standard of decisionmaking ability should be used to determine whether an individual is competent? Who should decide whether an individual retains personal liberties?

Background and Precedents

Society's role in questioning a person's competence and assigning him or her a surrogate decisionmaker is not a new one. Guardianship, and its concurrent notion of decisionmaking by a surrogate, dates back at least to ancient Rome. It was apparently conceived as a means of protecting the ward, or individual in question, and that person's property (7). That authority, based on the State's

police power and traditional role *as parens patriae*, imposes court-supervised external control over individuals not deemed capable of making informed autonomous decisions, such as minors or insane and incompetent persons (50).

State statutes govern incompetency and surrogate decisionmaking, resulting in multiple approaches. In general, however, standards prompting the need for a surrogate can be divided into three types (50):

1. **The Causal Link.** Once the most popular standard, it is still used in some States. Fundamentally, it entails diagnosis of a condition—i.e., a cause—that creates the socially improper behavior exhibited by the ward. That diagnosis generally precludes guardianship hearings for those who are perfectly capable of caring for themselves and their property adequately but who do not choose to do so (e.g., an eccentric person who decides never to bathe).
2. **The Uniform probate Code.** This standard is more concerned with the health, well-being, and safety of the individual than his or her property management. It also emphasizes an individual's ability to both make and communicate decisions as the litmus test for competency. Notably, some State variations on this standard limit a finding of incompetence to situations where the health, safety, and physical necessities of an individual are endangered.
3. **The Therapeutic Approach.** This approach is increasingly favored in gerontological and mental health circles. It defines a defendant incapacity as a legal rather than a medical state, measured by his or her functional limitations. Thus, a court finding is based more on a person's capacities than on a medical diagnosis, and specific dysfunctions must be proved.

Defining Competence

Competence to make decisions is not like a light switch that turns on or off. Many elderly persons may be partially competent, or able to make some decisions but not others. They may be intermittently competent—more lucid and able to make

decisions on some days than on others. Ideally, all individuals would be allowed to retain their autonomy and make decisions for as long as possible. Those who are partially competent would make decisions they are competent to make; those who are intermittently competent would make decisions when they were capable of making them. However, this ideal requires that “the task of competence clarification” (11)60 be of the greatest importance. It has been argued that:

The point of a competence determination is to sort people into two classes: those whose decisions must be respected, and those whose decisions will be set aside and for whom others will be designated as surrogate decisionmakers. Competence, then, is not a matter of degree—a person either is, or is not, competent to make a particular decision . . . [But] no single standard for competence is adequate for all decisions. The standard depends in large part on the risk involved, and varies along a range from low/minimal to high/maximal. The more serious the expected harm to the patient from acting on a choice, the higher should be the standard of decisionmaking capacity, and the greater should be the certainty that the standard is satisfied (11).

An individual either is or is not competent for a specific task, i.e., to make a specific decision regarding, for example, health care, living arrangements, or financial affairs. For competent decisionmaking, a person should have the capacity for communication, understanding, reasoning, and deliberation, plus a relatively stable set of values. Appropriate standards for competence should focus on the process by which a decision is reached, and not on the decision itself (1 1,20).

Determinations of competence—whether viewed as a matter of degree of capability or as an either/or matter—invoke two important values. First, the standard of competence must protect and promote an individual's well-being; second, it must respect an individual's right to self-determination (11). (For more discussion of this issue, see ch. 8.)

Functional assessment has been suggested as an aid in determining incompetence and subsequent delineation of decisionmaking powers by a surrogate (50). Functional assessment does not provide a diagnosis, only a description of behaviors; a judge may then evaluate whether such behavior indicates the need for a surrogate deci-

sionmaker. It is a tool to use in assessing an individual's physical and emotional ability to function on a daily basis, and, consequently, his or her need for a surrogate. One problem associated with the functional assessment standard of competence is that, without a medical diagnosis, an individual with a treatable condition may unnecessarily be judged incompetent.

One advantage of using functional assessment for individuals with dementia is that these disorders do not necessarily impair all areas of the brain equally, or even at the same rate. Thus, an assessment might support a person retaining some decisionmaking abilities, even if he or she is incompetent in other matters. However, some form of standardized functional assessment is needed—with a failure to attain basic levels of physical and intellectual sufficiency leading to a legal verdict of incompetency.

If an assessment takes place, the evaluator should apply the State's objective standards; the ward's previous mental and physical capacity are irrelevant. Assessments should be conducted by employees of community senior citizen centers, schools of nursing and social work, or public health departments, and presented to the court during surrogate appointment proceedings (16, 17)50).

Consequences of Incompetence

An individual found incompetent—by a doctor, a family member, or a judge—may be moved from home, have money and property managed, and be unable to refuse medical treatment. He or she will lose most decisionmaking rights.

Not everyone is competent to make the fundamental decisions faced by sick and elderly Americans. Who has a right to make decisions for another? What kinds of decisions can be made by one person for another? Should the surrogate have the right to make critical care decisions? How should a surrogate decisionmaker be chosen? What happens if a surrogate decisionmaker is not selected before an individual becomes incompetent? What can and cannot be accomplished through advance directives? What happens if there is no advance directive when someone becomes incompetent? How have the courts and the

medical community responded to the issues raised by surrogate decisionmaking and advance directives? Who, if anyone, is liable for decisions made by a surrogate?

These are the issues that are triggered by a determination of incompetence and form the basis for this chapter. There are no easy answers, and the questions themselves often act as lightning rods for controversy. In this largely undefined legal territory, highly personal family dilemmas can become public test cases.

Forums of Competence Adjudication

Strictly speaking, competence is a legal concept, but the legal and clinical standards differ considerably (30). Legally, an individual is presumed competent until a court declares otherwise and appoints a guardian (30). Practice differs from theory, however, in many cases of questionable competence. The determination of competence is usually made informally first by family or friends. The next informal determination is often made, with varying degrees of expertise, by the person's doctor, banker, or lawyer, who acquiesces to family requests to take responsibility for medical, fiscal, or legal matters.

Legal competency proceedings are rarely initiated for medical reasons. Instead,

... if an elderly person is deemed incompetent by caregivers, they usually turn to family members to make decisions on behalf of the patient. It is not clear why clinical practice so diverges from legal standards. Physicians may be ignorant about the precise legal definition of competency or may regard legal proceedings as too cumbersome and time-consuming, with insufficient benefits to justify the cost (30).

Families prefer to consult informally with the doctor in making decisions rather than go through the time, trauma, and cost of having someone declared incompetent. This is an efficient, if not extralegal, way of coping with the competency issues. Moreover, all parties may be happy with the arrangement—as long as they continue to agree on what constitutes appropriate treatment (13).

When mental status examinations are given, examiners check a patient's orientation, memory,

and ability to perform simple calculations (see ch. 8). However, mental status exams may not be able to assess a person's ability to comprehend medical treatments and alternatives, or their risks, benefits, and consequences. If a person's competence is questioned, a psychiatrist input is more likely to be sought than a court's. Such informal competency determinations, while often effective, do not provide due process of law and may unfairly prevent individuals from making personal decisions. The scope of this potential problem is unknown, but general consensus seems to be that almost all competence determinations are the result of genuine concern of families or friends.

Courts also make competence determinations. Adjudications of competence, however, occur most frequently when competence is disputed. For instance, a doctor may feel that an operation is necessary for the health of a patient who refuses to consent. If there is reason to believe the patient is incompetent, the doctor may initiate court involvement. Likewise, a family who is concerned over a relative's aberrant behavior may seek a court determination of incompetence and appointment of guardianship.

SURROGATE DECISIONMAKING

When a determination of incompetence is made, either formally or informally, the surrogate decisionmaker assumes power to act for the incompetent individual. Surrogates may be selected by someone in advance of incompetence, self-appointed, or appointed by a court.

Advance Selection

Persons with clear personal, medical, and estate preferences may issue an advance directive. Advance directives are designed to allow a competent individual's choices and instructions to be recorded, and then followed after the person becomes incompetent. However, few people thus far have planned for future incompetence by instructing someone on how they would like to be treated in the event they are unable to make their own decisions about health care (56, app. B). Many are ignorant of their options, reluctant to face the thought of disability, or intimidated by the legal system. Recently, however, various consumer groups have begun publicizing the advantages of identifying a surrogate and writing advance directives for extending a person's autonomy and obviating reliance on the courts (41). However, ambiguity in State statutes and the relevance of health care facilities make it uncertain that an individual's advance directive will be followed.

Durable Power of Attorney

Durable power of attorney (DPA) is a modification of the standard power of attorney that permits an individual (principal) to transfer specified powers to another person (attorney-in-fact). The power may be broad in scope or limited. The fundamental difference between standard and durable power of attorney is that the former loses its validity when the principal becomes incompetent, and thereby is not useful for persons with a dementing illness. Durable power of attorney, authorized by State statute everywhere in the United States except in the District of Columbia, provides a means of surrogate decisionmaker designation that survives the incompetence of the principal (46).

There are two types of durable power of attorney. The first takes effect on being signed by the principal and continues, unless revoked while the principal still has capacity, until death. The second, called a "springing" durable power, takes effect when the principal becomes incapacitated. In both types, the principal determines which powers are delegated to the surrogate. Concerned parties may petition a court to review the surrogate's actions.

The use of durable powers to transfer decision-making authority avoids many of the legal fees

and court costs associated with a conservatorship or guardianship, and does not require bonding or supervision. Additionally, it can fully represent the principal's choices and perspectives. Individuals may not be ready psychologically to execute this document before, or at the onset of, a dementia. For that reason and because of the generally progressive nature of impaired decisionmaking capacity, many lawyers recommend that already incapacitated individuals be brought to them during any reasonably lucid moment for explanatory purposes and signature (36,40).

There are other problems with durable power of attorney. Many banks and lending institutions are unfamiliar with it and may not accept a durable power as legal proof that the principal's finances are now under the control of another individual, unless the institution's own forms are used. That is impossible where the principal is already incompetent. Also, the validity of both types of durable power as applied to critical care decisions has been questioned in the courts and at patient bedsides (38,41,48).

Durable Power of Attorney for Health Care

California in 1983 passed legislation that created a new entity, the Durable Power of Attorney for Health Care (DPAHC). That power, also now available in several other States, attempts to address some of the issues surrounding the use of durable powers of attorney for critical care decisions (see table 5-1). It specifically empowers the attorney-in-fact to make medical care decisions. The DPAHC, which is a springing power, allows the principal to state, in detail, what kinds of medical intervention or life-sustaining systems are acceptable (22)24,36,41).

DPAHCs and living wills are the first legal measures that give individuals the ability to direct treatment decisions after incompetence. For people to make informed decisions, they need to be educated regarding their rights. They need to know what legal devices are available, under what circumstances they apply, and how to take advantage of them.

Living Wills

Living wills are another mechanism for expressing the principal's intent while competent and for honoring his or her desires once he or she is incompetent and death is imminent. A living will may declare the principal's intent on the use or refusal of life-sustaining procedures in the event the person cannot be reasonably expected to recover from extreme physical or mental disability. Statutes protect health care providers from civil and criminal liability for withholding or withdrawing life-sustaining treatment in compliance with a living will, and state that refusal of life-sustaining treatment by a terminally ill patient does not constitute suicide for insurance or other purposes. In most States, a physician who is unable to comply with a patient directive for religious or personal reasons is obliged to transfer the patient to the care of someone who can comply. Failure to transfer such a patient may constitute unprofessional conduct on the part of the doctor or hospital (47,63).

However, living wills are frequently ambiguous, lacking specific instructions tailored to specific medical needs, and may request something that the State is unwilling to countenance. For instance, uncertainty exists regarding an individual's right to refuse artificial food or hydration through the living will (30). The legality of living wills maybe unclear, and the document may draw uncertain responses from physicians. Nevertheless, or perhaps in response to these problems, the number of States with legislation on living wills is growing (see table 5-2). The States that did not recognize living wills as of July 1986 were Kentucky, Massachusetts, Michigan, Minnesota, Nebraska, New Jersey, New York, North Dakota, Ohio, Pennsylvania, Rhode Island, and South Dakota.

State-by-State variations include requirements for executing a valid living will and conditions making one applicable (see table 5-3). A document that is legally valid in the State where it was signed, for example, may not always be useful elsewhere. Most States provide a form that may be used to create a living will, but also permit individual variations as long as specific State requirements are

Table 5-1.—Special Requirements for Creating a Durable Power of Attorney for Health Care

State	Notary required	Filing required	Other
Arkansas	Yes (or approval of Probate Court)	Probate Court	
California ^a	Yes (or signed by two witnesses)		If patient is in nursing home, one witness must be patient, advocate, or ombudsman Must be accompanied by statutory notice or signed by an attorney Must be accompanied by statutory notice
Connecticut	Yes		Only a spouse, parent, adult child, sibling, niece, or nephew may be appointed
Florida	No		
Minnesota	Yes		
Missouri	Yes	Recorder of deeds	
New York	Yes		Must be accompanied by statutory notice
North Carolina	Yes	Register of deeds (copy with clerk of Superior Court)	
Oklahoma	No	Clerk of State District Court	Must be approved by judge of State District Court
Rhode Island ^a	No		At least one witness must not be related by blood, marriage, or adoption and must not be entitled to any part of the maker's estate
South Carolina	Yes	Register of Mesne Conveyance	Requires three witnesses
Wyoming	No	Clerk of District Court (copy with clerk of county court where principal resides)	Must be approved by judge of State District Court

^aCalifornia and Rhode Island have statutory forms for durable powers of attorney for health care which include a notice or warning to persons executing the document.

SOURCE: B Mishkin, "A Matter of Choice: Planning Ahead for Health Care Decisions," Senate Special Committee on Aging, 1986.

met. To avoid difficulties at the precise time the document is most needed, living wills are best drawn by a well-informed attorney. The States received some direction from the National Conference of Commissioners on Uniform State Laws in August 1985, when proposed uniform living will legislation was ratified, but there is still no consensus. Knowledgeable observers expect a more standard approach to be adopted by a significant number of States in the next few years (1).

States also differ in the conditions they set for a living will to become effective. Many States, for example, require a person to be "terminally ill" in order to activate a living will. However, there

is no clear definition of when an illness becomes terminal. As two observers note:

Some people may consider a person who is expected to live six months terminal, while others may regard a patient as terminal only when survival is expected to be one month or one week. Some physicians consider patients terminally ill only when they are moribund and will die in a few days no matter what treatment is given. Some people may consider a patient terminal when cancer is first diagnosed, while others apply this label only after metastasis develop or a relapse occurs after treatment (30).

If the diagnosis of "terminally ill" is taken to mean imminent death—as it frequently is—then such

Table 5.2.—Special Limitations on Living Wills (table complete as of September 1986)

State	Not valid during pregnancy	Categorically may not withhold food or fluids	Effective only for given number of years	Must sign after terminal diagnosis to be binding
Alabama	X			
Alaska	X ^a			
Arizona	X ^a	X		
California	X		5	X
Colorado	X ^a	X		
Connecticut	X	X		
Delaware	X			
Florida	X	X		
Georgia	X	X		
Hawaii	X			X
Illinois	X	X		
Indiana	X	X ^b		
Iowa	X ^a	X		
Kansas	X			
Maine		X		
Maryland	X	X		
Mississippi	X			
Missouri	X	X		
Montana	X ^a			
Nevada	X			
New Hampshire	X	X		
Oklahoma		X		X
Oregon		X ^c		
South Carolina	X	X		
Tennessee		X		
Texas	X			
Utah	X	X ^d		
Washington	X			
Wisconsin	X	X		
Wyoming	X	X		

^aIf fetus could develop to point of live birth.

^bMay not withhold "appropriate" nourishment and hydration.

^cMay withhold if patient cannot tolerate.

^d...ss declarant specifically authorizes.

SOURCE: B. Mishkin, "A Matter of Choice: Planning Ahead for Health Care Decisions," Senate Special Committee on Aging, 1986.

a requirement negates an incompetent individual's ability to direct medical care through a living will until the last few days or weeks (i.e., victims of serious accidents or strokes, who are in a persistent vegetative state, may not be considered "terminally ill" even if they would not wish to live for years in a coma if recovery were impossible). The living will also might apply in the case of elderly persons who are in an irreversible decline,

suffering from deterioration of various organ systems or the combined effects of degenerative disorders. Some States (California, Idaho, and Oklahoma) require living wills to be signed after a terminal diagnosis; thus, a living will would not help any of the patients just mentioned. Many of these people would not want to be kept on life-sustaining systems if they no longer had any awareness of life, but a living will statute relying

Table 5-3.—Witness Requirements for Living Wills (table complete as of September 1986)

State	Witness may not be:					Responsible for declarant's health care costs	Nursing home patient requires special witness
	Related by blood or marriage	Heir/claimant to the estate	Declarant's physician	Employed by declarant's health care facility	Declarant's physician or co-patient		
Alabama	X	X	X	
Alaska	X	
Arizona	X	X	X	
Arkansas	
California	X	X	X	X	X	Patient advocate or ombudsman
Colorado		X	or any M.D.	or co-patient	
Connecticut		
Delaware	"X"	X		X	X	X	Patient advocate or ombudsman
District of Columbia	X	X	X	X	X	X	Patient advocate or ombudsman
Florida	one of two witnesses	. ,	.				
Georgia	X	X	X	X	X	X	Medical director
Idaho	X	X	X	X	X	
Illinois	X	X		. . . ,	X	
Indiana	only parents, spouse, and children	X				X	
Iowa							
Kansas	X	X				X	
Louisiana	X	X	X	or co-patient			
Maine							
Maryland	X	X	X	X	X	X	
Mississippi	X	X	X				
Missouri							
Montana	. . . ,						
Nevada	X	X	X	X	X		
New Hampshire	X	X	X				Medical director
New Mexico							
North Carolina	X	X	X	X	X	.	
Oklahoma	X	X	X	or co-patient		X	
Oregon	X	X	X	X	X		Individual designated by Department of Human Resources Hospital or nursing home resident requires ombudsman
South Carolina ^a	X	X	X	X	X	X	
Tennessee	X	X	X	X	X		
Texas	X	X	X	or co-patient		,	
Utah	X	X	X	X	X	X	
Vermont	X	X	X				
Virginia	X						
Washington	X	X	X	X	X		
West Virginia	X	X	X	X	X	X	
Wisconsin	X	X	X	X	X		
Wyoming	X	X				X	

^aSouth Carolina requires three witnesses and notary

SOURCE: B. Mishkin, "A Matter of Choice: Planning Ahead for Health Care Decisions," Senate Special Committee on Aging, 1986

on "terminal illness" would not permit them to direct their own care and treatment after incompetence (47).

Informal, or Self-Selection

De facto surrogate decisionmaking, which is frequent, consists of an individual's assumption of the normal financial and personal decisions of

another without formally being charged to do so through legally recognized proceedings. De facto surrogates usually are a person's close relatives or friends. For many elderly individuals who do not plan ahead by appointing a surrogate through a durable power of attorney, de facto surrogate decisionmaking is easier and less traumatic than the guardianship process. In effect, de facto surrogates act on another's behalf in the same way

that court-appointed surrogates do—until such rare time as someone challenges their authority. The use of de facto surrogates eases the potential burden on the court system, but it also places people's liberties at risk. Legal advance appointment of a surrogate allows the principal a choice of surrogate that may differ from the de facto surrogate.

Many people rely on their physicians to make decisions for them. In most cases, particularly where there are also sympathetic family members involved, that approach is adequate. It is time-tested and remains the favorite of a vast majority of physicians (23). However, it presumes a strong concordance of views between physician, family, and facility. Also, nursing home residents are frequently transferred to acute care hospitals shortly before death (see ch. 10). Thus, the individual's regular nursing home physician, who may have agreed to a wish for nontreatment, might not be the physician responsible for the person's hospital care.

De facto surrogate decisionmaking is also more easily abused, as it occurs without a court's involvement. Only a legal challenge to the de facto surrogate's authority can initiate court review, and the decision to make that challenge can be traumatic and costly to the person bringing suit—an individual who may feel it is not his or her place to intervene. The dilemma is how to protect people who do not appoint or instruct a surrogate personally, without encumbering the court system or the emotional and financial resources of families. It is unclear if this is a problem; the number of persons affected is unknown and there is no available data.

Selection by Formal Appointment

Conservatorship and Guardianship

Conservatorships and guardianships are determined and supervised by the court. Specific State statutes and practices vary. There are two types: conservatorship (or guardianship) of estate covers finances; conservatorship (or guardianship) of person covers residency, certain kinds of health care and social service decisions, and other personal matters. The appointment is obtained by petitioning the court and presenting evidence of a person's relevant incapacity.

A guardianship proceeding generally requires two steps. First, a proposed ward must have a specified diagnosis or disability. Second, as a result of that disability, the proposed ward must be unable to make decisions on his or her own behalf. The Uniform Probate Code defines an "(incapacitated person)" as one "who is impaired by reason of mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication, or other cause (except minority) to the extent that he lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person" (58).

Courts and legislatures increasingly recognize that competence may wax and wane over time, and that patients may have the capacity to make some choices, but not others. In response, a growing number of States now permit limited or partial guardianship, in which surrogate decisionmaking authority is confined to specific areas. Some statutes allow courts to structure guardianship to fit the needs of an individual ward, while others require only that the guardian's powers be drawn as narrowly as possible (47).

Conservatorships and guardianships provide an incapacitated individual with as much legal protection, through court involvement, as possible. On the other hand, they can incur high and continuous legal fees (IS), increase demands on the judicial system, and offer no guarantee that decisions always will be made in the best interest of the incompetent person or in keeping with that person's desires.

Guardian ad Litem

Another form of guardianship occurs when a specific problem, such as authorization for surgery, must be solved by the court and one of the concerned parties needs representation. In this instance, a "(guardian ad litem)" may be appointed to represent an arguably incompetent person in that specific matter.

Representative Payee

A representative payee is, in effect, guardian of a patient social security or other government benefits. Neither conservatorship nor power of

attorney is recognized by the Social Security Administration, Veterans Administration, or many other government agencies as a legal basis for transferring benefit payments to a person other than the beneficiary. Many agencies specify that an individual wishing to act as a “representative payee” for someone must obtain a physician’s written statement that the beneficiary is incapable of handling his or her financial affairs.

The procedure for the appointment of a representative payee is much less formal than that entailed in a court competency hearing, the determination resting solely within the discretion of the head of the appropriate agency. In many cases the physician—whose recommendation will carry great credence—sees the patient only in stressful settings like the hospital or doctor’s office, and communicates with the patient only about medical care, not the handling of financial affairs. Government agencies may transfer payment monies to a representative payee even if the principal has not been deemed incompetent by a court (28,29, 53)74). Further, although empowered to request an accounting, government agencies do not ordinarily audit the activities of the 4 million to 5 million representative payees to ensure that the transferred monies are being spent in the interests of the principal.

This practice of nonscrutiny led to a 3-year lawsuit, instigated by a woman in Oklahoma, whose Supplemental Security Income payments had been fraudulently used by her representative payee sister for several years. In 1983, the U.S. District Court for the Western District of Oklahoma did find, among other things, that the due process clause of the fifth amendment required that the Social Security Administration implement mandatory, periodic accounting procedures. Margaret Heckler, Secretary of Health and Human Services and the defendant in the case, submitted a plan whereby 0.025 percent of representative payees would have their accounting short form reviewed (74). In 1984, the court found that the substantial interest of Social Security beneficiaries for whom representative payees have been appointed could be adequately protected only by requiring universal annual accountings. Although initially acquiescent, the Department of Health and Human Services (DHHS) returned to the court in April 1986

and requested, once again, that it not be required to request or review representative payee accountings pending further court decisions. The court granted that stay, and the future of accountings by representative payees remains in question (19, 28,62,70).

Further complicating this issue is the Social Security Disability Benefits Reform Act of 1984 (Public Law No. 98-460), Section 16 of which provides that where payment is made to a person other than the entitled individual, an annual accounting is required, with the Secretary establishing and implementing “statistically valid procedures for reviewing such reports.” DHHS has not implemented this requirement. Section 16 also sought a report to be prepared for Congress in 1985. That report was to examine the systems by which accountings would be reviewed, the problems inherent in the systems, and the problems inherent in the representative payee system. A six-page report was submitted in September 1985, containing no data on rates of auditing, no details about ascertaining mental competence for purposes of assigning representative payees, no description of procedures for identifying misuse of funds, and no special safeguards for those judged mentally incompetent who are cared for outside State mental institutions (19,68).

Family Consent Statutes

Under family consent statutes, a surrogate is identified in advance by the State and is automatically vested with certain powers, unless an individual has previously designated a different surrogate decisionmaker. Seventeen States have enacted laws clearly authorizing family members to make health care decisions on behalf of incapacitated adults—at least for those who are terminally ill (see table 5-4). Case law in California, Connecticut, Florida, Georgia, and New Jersey supports the right of family members to make health care decisions, including decisions to forgo treatment, for terminally ill or comatose patients. The family consent statutes remove doubts surrounding the legal basis for such decisions and permit doctors and other health care providers to follow the directions of family members without fear of subsequent civil or criminal liability (47). The provisions become effective when a patient is incompetent, but the majority of statutes do not at-

Table 5-4.—Family Consent Provisions

Provisions	State	Statute	
Family may make health care decisions for incapacitated adults	Arkansas	Ark. Stat. § 82-363 (1976)	
	Georgia	Ga. Code §31-9-1 (1982)	
	Idaho	Idaho Code § 49-4303 (1985)	
	Louisiana	L.a. Rev. Stat. Ann. tit. 40, § 1299.53 (1977)	
	Maine	Me. Rev. Stat. Ann. tit. 24, § 2905 (1985)	
	Maryland ^a	Md. Ann. Code § 20-107(d) (1984)	
	Mississippi	Miss. Code Ann. § 41-41-3 (1985)	
	Utah	Utah Code Ann. § 78-14-5(4) (1977)	
	Family may make health care decisions for terminally ill and incapacitated adults (including termination of treatment)	Florida	Fla. Stat. Ch. 84-85, § 765.0 (1984)
		Iowa	Iowa Code Ch. 144A.1-144A.12 (1985)
Louisiana		L.a. Rev. Stat. tit. 40, § 1299.58.5(A) (H.B. 795, 1985)	
New Mexico		N.M. Stat. Ann. § 24-7-5, as amended by S.B. 15 (1984)	
North Carolina ^b		N.C. Gen. Stat. § 90-322(b), as amended by S.B. 240 (1983)	
Oregon ^b		Ore. Rev. Stat. § 97.083(2), as amended by H.B. 2963 (1983)	
Texas		Tex. Civ. Stat. Art. 4590h, as amended by H.B. 403 (1985)	
Virginia		Va. Code Ann. § 54-325.8:6 (1984)	
Utah ^c		Utah Code Ann. §§75-2-1101-1118 (1985)	

^aExcludes sterilization, abortion, and treatment or hospitalization for a mental disorder.

^bPatient must be comatose.

^cOriginal law, passed in 1977, specified only incapacitated adults.

SOURCE: B. Mishkin, "A Matter of Choice: Planning Ahead for Health Care Decisions," Senate Special Committee on Aging, 1986.

tempt to define incompetence or require a formal competency hearing. Thus, the competency determination generally is made by the physician. Since most of these provisions are built into living will statutes, only families of the terminally ill are eligible to use them (see table 5-5).

The National Conference of Commissioners on Uniform State Laws adopted a Model Health Care Consent Act in 1982 (67). The model act states that when a patient is incompetent to consent to or refuse treatment, and has not designated a surrogate decisionmaker, decisions may be made by a spouse, adult child, parent, or adult sibling. Unlike some State statutes giving priority to one family member over another, the model act does not differentiate between family members, nor does it suggest how to proceed if family members disagree. It does emphasize that surrogate decisionmakers should base their decisions, inasmuch as possible, on the patient's previously expressed preferences. Thus far, the model act has had little effect on actual State legislation.

Alternative Forms of Surrogate Decisionmaking

Public guardianship programs vary somewhat from State to State, but typically are overseen by a county office of the public guardian, ombudsman, or court investigator. These offices supervise and manage guardianship cases, sometimes appointing private individuals as conservators where there are substantial estates. In these cases, it is not uncommon for a financially sophisticated "friend of the court" to be appointed (48).

The private practice of surrogate management is also becoming more common. Here, bonded individuals manage estates on behalf of their clients for a fee. Because of difficulties in some public guardianship programs, private for-profit programs are gaining some favor in the legal community. As a safeguard, it has been suggested that these private programs be subject to regular reporting requirements (10,39,49).

Table 5-5.—individual State Provisions of Family Consent Laws

State	Patient must be		Family members				Priority given	Consent not valid for		
	Terminally ill	Comatose	Spouse	Adult child	Adult sibling	Other		Abortion	Sterilization	Mental health care
Arkansas			X	X	X	nearest relative				
Florida	X		X	X ^b	X	nearest relative	X			
Georgia			X		X ^a	X ^a grandparent	X	X		
Idaho			X		X	any competent relative				
Iowa	X		X	X ^b	X	X				
Louisiana			X		X ^a	X ^a grandparent		X	X	
Louisiana	X		X	X	X ^b	X ^b other ascendants or descendants or nearest relative	X			
Maine			X		X	nearest relative				
Maryland			X	X	X	X grandparent	X	X	X	
Mississippi			X	X	X	X grandparent				
New Mexico	X or	X	X	X	X	family members ^d	X			
North Carolina	X and	X	X	X	X		X			
Oregon	X and	X	X	X ^b	X	X				
Texas	X		X	X ^b	X	nearest relative	X			
Utah			X	X	X ^a	X ^a grandparent				
Virginia	X		X	X	X	nearest relative	X			

^aFor minor child

^bMajority of this class required (if available)

^cLouisiana has two family consent laws

^dAll who can be contacted must agree on what patient would choose

^eRequires consent of at least two family members, if reasonably available

SOURCE: B. Mishkin, A Matter of Choice: Planning Ahead for Health Care Decisions. Senate Special Committee on Aging, 1986.

There are also numerous private social service organizations that assist in establishing eligibility for public benefits. They generally support family members who may live too far away to be of help on a daily basis. Families may use this method to avoid the trauma and cost of a court hearing on conservatorship.

Hospitals and nursing homes also designate surrogates, such as patient advocates or ombudsmen. However, because the nature and philosophy of each facility can vary, defining the role of surrogates designated in this way is difficult. These surrogates typically act more as advocates than decisionmakers or case managers. In addition, because the surrogate is employed by the hospital or nursing home rather than the patient or resident a conflict of interest may occur. Cases of financial abuse where surrogates are employed by a facility have been documented (3,5,23,25,26,69, 71).

Occasionally, when an individual has no surrogate decisionmaker or when there is disagreement between family members and caretakers, an institutional ethics committee (IEC) maybe used to assist in making a decision. Ethics committees are becoming a popular means of considering difficult medical treatment situations on behalf of an incompetent individual. They received their initial stamp of approval when the New Jersey Supreme Court proposed that such a group play a role in the decision about whether to disconnect Karen Anne Quinlan's respirator. In that instance the committee was to provide a prognosis for Quinlan's recovery, the outcome of which would help determine the court's decision (35)59, 72).

These committees have faced numerous operational questions, however (64)65). In 1983, only 1 percent of the Nation's nearly 2,000 acute care hospitals had a functioning IEC. That same year,

the first national conference on IECs was held (Institutional Ethics Committees: Their Role in Medical Decision Making, sponsored by the American Society for Law and Medicine and Concern for Dying, Washington, DC, Apr. 21-23, 1983). In addressing what role an IEC may play, one law professor drew up three possible models:

1. in the "optional-optional" model, the committee acts on a standby basis, with no one being required to make use of its services or abide by its recommendations;
2. in the "mandatory-optional" model, physicians would have to consult the IEC when faced with a critical decision, but would not be required to adhere to its recommendations; and
3. in a "mandatory-mandatory" model, physicians would be compelled to consult the IEC when faced with a critical decision, and compelled to carry out its decision (61).

One underlying dilemma of IECs has been put this way:

Either ethics committees will have well-grounded criteria for making recommendations in particularly difficult cases, or they will not. If such criteria are widely accepted, the committee seems redundant; why not appeal directly to the criteria? And if such criteria are not widely accepted, the committee recommendation may seem arbitrary and fail to persuade some of those whose decisions the committee is reviewing (Callahan, as quoted in 34).

Despite these lingering questions, ethics committees are increasingly used in the hospital setting. There is some support, at least in the nursing community, for IECs having the authority to make legally binding critical care decisions (31,44).

Several other unrestrictive, extralegal alternatives to conservatorship of person are referral, case work, and case management. (For more information on these nonlegal alternatives, see ch. 6.)

The Influence of Setting

How a surrogate is chosen depends, in part, on the person needing the surrogate and his or her environment. Those choosing a surrogate from home frequently rely on family, friends, the local banker, the personal physician, and others who compose the informal support network.

In domiciliary care facilities (DCF) or board and care homes, the operator or a staff member may be acting as the surrogate—with or without formal legal appointment or even informal approval of the patient. That is problematic. These facilities generally are not as well defined or visible in a community as a nursing home. They frequently are supervised haphazardly if at all, by government agencies. Many are unlicensed and lack the benefit of ombudsman involvement. Because reporting responsibilities are few, surrogate decisionmaking generally devolves to the DCF operator with no external oversight (26)53,69).

Special problems may exist for those residents of nursing homes who have no interested relatives or friends. For those individuals, medical decisionmaking often consists of informally turning to a doctor or the nursing home staff, with some input from any available relatives. That is particularly true of Medicaid patients without concerned families, who lack large material assets to attract potential surrogate managers. Decisions are quite often made by physicians with some input from any members of the family who are available.

In hospital settings, patients may be in rapidly failing health, clearly incompetent, diagnosed as "terminal," or headed for a nursing home. Hospital administrators are wary about encouraging patients to sign documents appointing surrogate decisionmakers and about giving what maybe considered self-serving advice. They have expressed concern that the acute care environment is inconsistent with the concept of competency and that they will be charged with the responsibility of certifying competence in all cases. Additionally, they worry that liability insurance coverage will be jeopardized by their delving into an area that is not formally part of their health care mandate (23).

The incompetent or questionably competent person in these health care settings has a role in selecting a surrogate. Even when there is some question as to the individual's capacity for decisionmaking, courts tend to respect that individual's decision. Nevertheless, patients, family members, caretakers, and social workers need to be educated and encouraged regarding the prompt identification of a surrogate (45).

DECISIONS MADE BY A SURROGATE

The previous section identified the various types of surrogates, explained how they are selected, and detailed the extent of their powers and limitations. Once a surrogate is in place, he or she must begin the sometimes difficult task of making decisions. How does a surrogate make crucial decisions for an incompetent person? What criteria does the surrogate take into account? What conflicts of interest might the surrogate encounter in making a decision? Who is liable for decisions made by the surrogate?

Criteria for Making Decisions

Once a patient has been deemed incompetent to make all or some decisions, some complex issues arise. Who should decide for the incompetent patient? By what set of principles should decisions be made? These questions have been addressed in dramatically different ways. Answers to the first question have been sought from a legal perspective, but answers to the second tend to be explored from an ethical framework. Thus, decisionmaking no longer is clarified by court rulings and State legislation; it operates in the ambiguity of what is right, or good, or ethical.

Briefly, various ethical principles can guide a surrogate in making a decision. The most fundamental of these are:

Ethical value principles identify the basic ethical values to be used in dealing with incompetent individuals. These values include respect for autonomy, concern for well-being, and justice in a patient's access to care and resources. Guidance principles give hints or direction as to how decisions should be made. These principles include: 1) substituted judgment, or choosing the way the individual, if competent, would choose; 2) best interest, or choosing what most benefits the individual; 3) advance directive, or choosing the way the individual has expressed in a previously written directive, such as a living will (11).

It is useful to compare and contrast these three guidance principles to understand how the use of one or another may vastly alter the outcome of the surrogate's decision.

The Best Interest Principle states that a surrogate is to choose what will best serve the patient interests. The qualifier "best" indicates two important factors: some interests are more important than others in that they make a larger contribution to the patient's good, and a particular decision may advance some of the patient interests while frustrating others. Thus, according to the Best Interest Principle, the surrogate must try to determine the net benefit to the patient of each option, after assigning weights reflecting the relative importance of various interests affected when subtracting the "costs" from the "benefits" for each option.

In contrast, the Substituted Judgment Principle states that a surrogate is to choose as the patient would choose if the patient were competent and aware both of the medical options and of the facts about his or her condition, including the fact that he or she is incompetent. Thus a surrogate who must decide whether antibiotics should be given to an unconscious man with terminal cancer might consider the following as a test of the Substituted Judgment Principle: "If the patient miraculously were to awaken from his coma for a few moments, knowing that he would soon lapse back into it, would he choose to have antibiotics administered?"

[The Advance Directive Principle] states that where a clear and bona fide advance directive is available, it is to be followed. There are two broad types of advance directives: *instructional* and *proxy* An instructional advance directive is an instrument whereby the patient when competent, specifies, perhaps only in rather general terms, which types of treatments he or she wishes to have or, more commonly, not have, under certain circumstances, should the person become incompetent In a proxy advance directive, a competent individual designates some other individual or individuals to serve as the surrogate should the person become incompetent. These two types of advance directive maybe combined: An individual might designate his or her spouse as proxy but include instructions that place limits upon that person's discretion to decide the individual's fate (11).

Which principle is followed may make a life-and-death difference to the patient. For example, acting in the patient's best interest may not be

the same as acting on substituted judgment or following an advance directive. Simply put, competent people sometimes make choices contrary to their own best interests, so these principles can be incompatible at times.

Further, following substituted judgment may lead to a different decision than following an advance directive. What a person would choose if he or she were competent during an illness may be different from what the person would choose at an earlier time, projecting ahead to a time of incompetence and illness.

Since following different principles may yield different results, it is necessary to assign them some priority in resolving situations where more than one principle could be used. In addressing this issue, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research proposed that where a valid and clear advance directive applies, it should take precedence over any other guidance principle, including best interest and substituted judgment (57).

Why Surrogate Decisions Are Not Always Respected

Despite the legally approved role of surrogate decisionmakers, their decisions may not be followed. There is no single explanation why decisions by court-appointed or de facto surrogates are not necessarily implemented. The uneasy coexistence of law and medicine, the perceived and actual authority of physicians, the emergence of medical technologies that prolong life, quality-of-life issues, a nationally heightened sensitivity to individual autonomy, an increasingly litigious society, and a growing population of incompetent elderly Americans all have contributed to the current legal, ethical, medical, and moral confusion over critical care decisionmaking by surrogates. Questions raised by surrogate decisionmaking have been present all along, but now they are complicated by new options for medical treatment, the multitude of decisions to be made at each step in a disease, and the sheer number of cases.

The Chairman of the President's Commission addressed this issue in a report on decisions to forgo treatment:

Although our study has done nothing to decrease our estimation of the importance of this subject to physicians, patients, and their families, we have concluded that the cases that involve true ethical difficulties are many fewer than commonly believed and that the perception of difficulties occurs primarily because of misunderstandings about the dictates of law and ethics. Neither criminal nor civil law precludes health care practitioners or their patients and relatives from reaching ethically and medically appropriate decisions about when to engage in or to forgo efforts to sustain the lives of dying patients (57).

Nonetheless, misunderstandings about the dictates of law persist, and can strongly influence medical decisionmaking and action:

Undue concern with imagined legal requirements and consequences may cause the physician to neglect or devalue other, seriously significant factors that should figure prominently in the calculus of withholding or withdrawing life-prolonging treatment (30).

The assessment of a patient's competence and the allocation of decisionmaking authority also may become hopelessly lost in the context of medical practice. Three separate studies of decisionmaking in "do not resuscitate" orders of patients found that 18 to 20 percent of competent patients, and 19 percent of the families of incompetent patients, did not participate in decisionmaking (37). A study conducted later at three other teaching hospitals found that for 78 percent of patients who were to be resuscitated, the decision was made without either patient or family input (21). Yet there is evidence that physicians are unable to determine accurately patient preferences about resuscitation without asking them directly. Reasons given by physicians for not involving either patient or family in such decisions include family requests that the patient not be involved, patient requests that the family not be involved, the belief that the doctor already knows what the patient wants, physician awkwardness in broaching the subject with the family, and the physician's belief that medical indications were decisive (4).

Physician uncertainty over the authority of advance directives is evidenced by data showing that most doctors would not resuscitate their patient in the event of cardiac or respiratory arrest if the patient had left written instructions not to pro-

long life through artificial means. However, if a patient left written instructions to do everything possible to prolong life, only about half the physicians polled said they would resuscitate (56). If some physicians question the authority of advance directives, still others appear to be unaware of their patients' treatment preferences. Several studies indicate that physicians often do not have a good understanding of their patients' wishes concerning resuscitation, and that although they agree that such matters should be discussed with their patients, they actually do so infrequently (4). A recent report on State Medical Disciplinary Boards by the American Medical Association includes physician "failure to comply with natural death act or failure to transfer patient care when physician cannot comply with patient's request to withhold life-sustaining treatment" as grounds for disciplinary action (63).

Questions of Liability in Medical Decisionmaking

... Traditionally, law and medicine did not occupy an antagonistic relationship. Rather, this relationship was fundamentally a symbiotic, mutual, and cooperative one. In fact, the medical profession has aggressively co-opted the legal system over the years and used the law's authority to serve its own ends. Illustrations of this interaction include the medical profession's traditional power to determine for itself the standards of care to be applied in a malpractice action, the standards of information disclosure that constitute informed consent, and licensure/discipline standards for determining who is allowed to be a part of the medical profession. The role of government in influencing such standards has historically been negligible (30).

A physician or other health care provider may not administer treatments, diagnostic tests, or surgical interventions without the consent of the patient. If medical interventions are administered without consent, the doctor and health care facility may be sued for assault and battery or for negligence (47,55). That precept was upheld in a recent case, when relatives of a patient who was placed on a life-sustaining system after she suffered a respiratory-cardiac arrest that left her in a chronic vegetative state filed action seeking damages for the time the patient was on life-

sustaining systems. Although the trial court dismissed the motion, the Court of Appeals of Ohio, Summit County, reversed the decision and held that "a cause of action exists for wrongfully placing and maintaining a patient on life-support systems, contrary to the express wishes of the patient and her family" (33). The second trial was decided in favor of the doctor, and the hospital privately reached a financial settlement with the family before the verdict was reached. During a second appellate proceeding, the doctor also privately settled with the family (73).

Complicating matters, however, is the distinction often cited between withholding [not starting] treatment and withdrawing or removing it. Although philosophers have argued that there is no significant moral difference between the two acts, many caregivers continue to worry that stopping existing treatment—like a mechanical ventilator or chemotherapy—may be considered direct action that entails higher liability risk (6, 18,27,30, 66).

Grayer still is the question of whether doctors recommend treatment in these cases because they believe it is clinically indicated or because they are concerned about their liability if they do not—no matter what the family wants (30). Ironically, although unwanted cessations of treatment theoretically may lead to lawsuits, there are numerous cases of families seeking a court order to stop treatment, but court orders to continue treatment have been sought only rarely and in unusual circumstances (1).

Physicians, however, perceive themselves in a double bind. On one hand, families increasingly request that treatment be withheld or withdrawn; on the other hand, in 1982 two California physicians were charged with first degree murder after discontinuing mechanical ventilation and intravenous fluids to a persistently vegetative patient—even though the family had asked that this treatment be discontinued (2). Although that case was dismissed by a court of appeals and remains one of a kind, it made a deep impression on physicians (30). More recently, the Massachusetts Supreme Court upheld the right of an incompetent patient not to receive nutrition and hydration through a gastrostomy tube. Although it was widely agreed that the patient would not

have wanted such treatment, his health care facility refused to discontinue it. The court, which respected the facility's decision, ruled that the patient must be transferred either to his home or another facility willing to comply with his wishes (9).

Questions of Abuse of Surrogate Decisionmaking Powers

Theoretically, a person with a dementing illness has the same right as any other individual to bring suit against those associated with his or her care. In practice, however, that may prove difficult. Where an individual has been formally deemed incompetent, has a history of confused behavior, or has depended on a de facto surrogate or attorney-in-fact, that person's views and statements are seriously discredited both in the courts and in the community. Moreover, people with dementing conditions may be suspicious, paranoid, and argumentative as part of the normal course of their diseases. Thus, while a person has ample theoretical recourse against abuse, those suffering from dementia are poorly situated to avail themselves of it. They must rely on the concern and advocacy of others.

The legal options against abuse of surrogate powers vary. De facto surrogates, with no formal power, could be challenged by another person. Where power of attorney has been granted and the principal is still competent, the principal may revoke the status of the attorney-in-fact. Although the ordinary power of attorney is not legally recognized where the principal is no longer competent, it may continue in fact until challenged by a concerned individual. A durable power of attorney could also be challenged in court by another person on the basis of abuse. For guardians or conservators, another individual or the court (under its continuing jurisdiction to review conduct) might challenge an abuse of decisionmaking power.

Individuals as Research Subjects

Progressive dementias—and especially Alzheimer's disease—can be difficult to diagnose, understand, and treat. There is compelling justification for research directed at understanding and controlling or preventing these diseases. The na-

ture of the illnesses limits the use of animal research models, and human subjects are necessary for even the early stages of scientific research. Thus, the social value of finding a cure or prevention for progressive dementias must be balanced against the protection and best interests of individuals who cannot understand or consent to research participation (42,52).

Until the early 1970s, individuals in prisons, mental health facilities, and nursing homes were readily used as research subjects.

These groups presented unique research opportunities because of the researcher's ability to carefully control and monitor the subject and his environment and to find subjects who willingly or unwillingly could participate in studies. The research projects, which ranged from the nonintrusive to the very intrusive, included a wide variety of studies aimed at obtaining information on medical and psychological problems. Few bothered to question the propriety of using the mentally disabled for these purposes. By the early 1970s the public's attention was focused on certain research projects that were difficult to categorize as anything but abusive. For example, it was disclosed that some retarded residents at Willowbrook State Hospital in New York had been deliberately infected with viral hepatitis and that many of the residents then contracted this illness. It was also revealed that 22 geriatric patients at the Jewish Chronic Disease Hospital were injected with foreign cancer cells without their knowledge or consent (8).

These revelations led to public concern over unconsenting mentally disabled individuals being used in any research, and to the congressional establishment of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in 1974. Some restrictions on when the mentally disabled may be used as research subjects, along with measures to protect the disabled who do participate in research, resulted from the Commission's and the public's concern over this issue. Federal guidelines provide little specific legal and ethical guidance, however, as applied to elderly individuals with dementia.

Even if an elderly person with a dementing illness could give prior valid consent, as an advance directive in a durable power of attorney or

through a decision made by a surrogate, there would still be the question of continuing consent: As research experimentation grows and changes, would the incompetent subject or surrogate still be in favor of any specific experiment and what kind of mechanism would enable him or her to choose to participate on a case-by-case basis (51)?

In November 1981, the National Institute on Aging held a conference on the ethical and legal issues related to informed consent for Alzheimer patients. That meeting led to the creation of a task force to formulate guidelines for use by researchers, policy makers, and institutional review boards (IRBs) concerned with experimentation regarding Alzheimer's disease or involving Alzheimer patients (43). In addition to proposing guidelines, the task force suggested that IRBs might want to encourage: 1) the development of a Federal policy on minimal-risk research that could guide State efforts to draft legislation regarding surrogate decisionmaking for research participation by incompetent individuals, and 2) the establishment of a national research ethics advisory body with authority to endorse or prohibit specific research protocols. Endorsement would be evidence of compliance with Federal regulations.

The suggested guidelines were supplied by the task force with these aims:

... 1) to express a preference for research with patients who are competent or who are otherwise relatively less vulnerable to potential abuse; 2) to identify individuals who are favorably inclined to participation in research and to provide mechanisms for their participation now and in the future, subject to necessary safeguards; 3) to assure that all research protocols involving (Alzheimer) patient-subjects have adequate mechanisms to assess competence, assure the adequacy of the consent process, and assure the continued ability of the subjects to decline to participate or withdraw; 4) to indicate special considerations in and limitations on research involving patients who are not capable of granting legally effective consent on their own behalf (43).

Ten guidelines on these issues were drawn up. Among other recommendations, the task force suggested that IRBs be particularly sensitive to protocol design and methodology involving sub-

jects who lack capacity to give consent, who do not object to consent, or who have not given prior consent through a durable power of attorney or otherwise. Research involving such individuals may be roughly classified into three different groups:

1. nonintrusive, noninvasive data collection and observation, and invasive research posing no more than minimal risk to subjects;
2. invasive research posing more than minimal risk that offers some realistic possibility of direct therapeutic benefit to the subject; and
3. invasive research posing more than minimal risk that does not offer some realistic prospect of direct therapeutic benefit to the subject.

The task force suggested that, where applicable, subjects should be selected in the following order of preference:

1. noninstitutionalized, still-competent individuals with Alzheimer's disease who decide whether or not to participate;
2. noninstitutionalized individuals with Alzheimer's disease and with impaired competence who had earlier competently expressed, and still express, a willingness to participate in research;
3. noninstitutionalized individuals with Alzheimer's disease and with impaired competence who express a current willingness, with family support, to participate in research; and
4. other noninstitutionalized individuals with Alzheimer's disease and with impaired competence who express a current willingness to participate in research.

The task force maintained that consent forms and other appropriate IRB safeguards be required for subjects with Alzheimer's disease who have the capacity to provide or refuse legally effective consent. Long-range protocols should be developed in which valid subject consent could be obtained during the early stages of dementia. For individuals with a dementing illness, greater scrutiny of the subject's capacity to provide consent should occur. Other factors to consider include the risks posed by specific research, the likelihood that the subject is to receive direct benefits, and the complexity of the research. The task force also

recommended that IRBs ensure that research protocols include a mechanism to designate a “legally authorized representative” or surrogate decision-

maker when a subject lacks the capacity to provide valid consent to participate in research, but does not object to participating.

ISSUES AND OPTIONS

It has been said that laws function best when they are the end product of social consensus (30). Laws that precede consensus on divisive issues often act as lightning rods for continued unrest and controversy. Furthermore, action by the Federal Government that is later overturned by the courts only serves to confuse the public, and put into limbo the lives of directly affected individuals.

Consensus on the issues raised by surrogate decisionmakers is slowly forming in the courts and State legislatures. Allowing this consensus to mature is perhaps the only way to ensure lasting constituent support and agreement on these issues. Some of the issues presented here may be more quickly and easily resolved than others, and might be safely legislated upon at this time; others might more wisely be left to further public debate. Most options detailed in this section could be accomplished by State, as opposed to Federal legislation, except where noted.

ISSUE 1: Should a standard method of determining competence to make health care decisions be adopted, or institutional checks on such determinations be introduced?

Option 1: *People could lose their right to self-determination upon diagnosis of a dementing disorder.*

Option 2: *Let physicians decide whether a patient with a dementing disorder is competent to make decisions.*

Option 3: *Base the determination of competence on a patient's demonstrated understanding of a treatment and its consequences—and of a refusal of treatment and its consequences.*

Option 4: *Consider competence to be decision-relative.*

Option 5: *Require court hearings for each person whose competence to make health care decisions is questioned.*

Option 6: *Form institutional committees to review the competence of a patient if competence is questionable or there is disagreement between physician and patient.*

Option 7: *Rely on a standing body of physicians, nurses, social workers, lawyers, mediators, laypeople, and others to act as an informal court, making competency determinations on a community or regional basis.*

Option 8: *Encourage health care facilities, such as hospitals and nursing homes, to develop and announce institutional policies and procedures for determining competence.*

Option 1 would obliterate the rights of individuals who are diagnosed early in their diseases, yet permit self determination for other individuals who have long since become incompetent but never had the benefit of diagnosis.

Letting physicians determine competence (option 2) is, for the most part, the status quo. One of the difficulties here is that a physician's religious, cultural, and moral beliefs and preferences may conflict with those of a patient. Often physicians deem patients competent when they consent to treatment, but incompetent when they refuse to continue the same treatment at a later date (32). This option also denies the patient due process of law before stripping him or her of decisionmaking powers.

Physician assessment of a patient should not be disregarded as an option, however. Frequently the physician (or other professional caretaker) is the most objective member of the patient-physician-

family triangle, and has motives that are less clouded by grief, trauma, or guilt. The physician is likely to have the most experience in assessing individuals with dementia. Option 2 does not incur the expense or time of a court competency hearing. If family members and other professional caretakers agree that the patient is incompetent, this approach generally is suitable.

Option 3 focuses on a patient's understanding of the consequences of a health care decision, not on whether the person agrees or disagrees with the physician or with family members. Safeguards might be instituted to ensure that adequate information to aid an informed consent or refusal is given to each patient prior to a treatment decision. A patient's comprehension of a proposed treatment is crucial to a competent decision, yet physicians have not always given sufficient time and effort to explaining treatments and consequences clearly. Devising adequate informational safeguards (e.g., peer review) would be challenging, but could result in better informed decisions.

The more important the decision and its ramifications, the more careful should be the assessment of competence—a point acknowledged by option 4. If the decision and its ramifications are not life-threatening or particularly vital, the patient's preferences might be more readily upheld. Guidelines for evaluating the difficulty of decisions in relation to a patient decisionmaking capacity could be created either by government or individual health care facilities. Devising and implementing such guidelines would take effort, but the advantage of option 4 is that such a system protects an individual's autonomy for as long as possible while still safeguarding health and safety.

Option 5, although it might safeguard the rights of some patients, is time-consuming, expensive, and traumatic for patients, family, and physicians. The judicial process often proceeds too slowly for medical needs. Such a proposal could also unduly burden the courts. However, if the judicial system could be streamlined to review competence effectively and efficiently, then a mandatory court hearing when a person's competence is questioned might present the enormous advantage of assuring each person the benefit of due process before losing the right to make decisions.

Institutional review committees—option 6—might be similar to the institutional ethics committees discussed earlier. Organization and operational questions regarding IECs, however, also would apply to this sort of competency review.

The advantage of such a committee would be that the patient right to self-determination might be better protected. A committee with members having diverse beliefs and values might make the decision regarding a patient's competence a more neutral and balanced one.

The disadvantage of option 7 lies in the unknown composition and funding of a standing review group, although many health care facilities, insurance companies, and other institutions might agree to fund and staff it. There also maybe questions regarding the group's expertise, methodology, and authority. The advantages include the independence of the group's members. Moreover, the assessment resources offered by such a group might be greater than those of an individual physician, hospital, or nursing home. A standing review group might also be an appropriate mechanism for determining competence to make nonmedical (e.g., financial) decisions. The group might be used for all competence determinations, or only when competence is questionable or in dispute. It might also recommend judicial action when unable to determine an acceptable resolution itself.

Option 8 could include developing a list of who is responsible for determining competence, effective safeguards against error and abuse, and an indication of when court intervention is appropriate. Many facilities already have such policies but either do not formally advise prospective patients of them or do not adhere to them. There is also a possible conflict of interest if health care facilities not only determine competence but also prescribe care. The advantage of option 8 is that patients and families could act as consumers—judging the stated policies and procedures of each facility and choosing the one most closely aligned with their own preferences. More importantly, patients and families have a right to know and understand the policies of their health care facility. Armed with that knowledge, the determination of competence for a given patient might be

demystified, and patients and families might be better able to make informed consents or refusals.

ISSUE 2: Should a uniform definition of terminal illness be adopted?

Option 1: Refrain from adopting a uniform definition of terminal illness.

Option 2: Define terminal illness as the few days or weeks when death is imminent.

Option 3: Define terminal illness as occurring at some stage earlier than a few weeks preceding imminent death.

Option 4: Amend living will statutes to apply to health care decisions at any time, not solely at the point defined as 'terminal illness.' "

The disadvantages of option 1, which is the status quo, have been discussed previously. The advantage of doing nothing now is that a societal consensus on this issue may form which law could then be enacted to embody.

Option 2 would give physicians, rather than patients, almost exclusive right to make treatment decisions until the very end of life. Further, it would strip most decisionmaking powers from surrogates and directive powers from advance directives.

A broader definition—option 3—would allow patients wishing to do so to execute advance directives to ensure withholding or withdrawing of treatment. It also would allow surrogates to act on the desires of the patient at an earlier stage.

Option 4 would allow incompetent patients who previously executed clearly defined directives or legally appointed a surrogate to have their medical treatment desires met through the course of their illness.

Living wills, family consent provisions, and durable powers of attorney mainly revolve around critical care decisions. Many statutes pertaining to these mechanisms, including living will statutes, depend on the diagnosis of a patient as terminally ill. With no standard definition of that term, confusion surrounds the application of these legal devices.

ISSUE 3: Could the identification of surrogate decisionmakers be encouraged?

Option 1: Require people to identify a surrogate decisionmaker when their tax status changes, or periodically.

Option 2: Give tax credits or deductions for the identification of a surrogate, or penalize people who have not identified a surrogate by a certain age.

Option 3: Require people claiming deductions for home or day care of their parents or spouses to document that a surrogate decisionmaker has been identified.

Option 4: Make enrollment into social service, health, and income maintenance programs contingent on identification of a surrogate,

Option 5: Encourage hospitals, nursing homes, other health care facilities, and board and care homes to institute procedures requiring or identifying surrogates of all entering persons.

Option 6: Expand the family consent provisions in State law.

Option 7: Encourage States to define precisely what powers are accorded surrogate decisionmakers.

Option 8: Impose sanctions against caretakers, facilities, or even family members who refuse to follow a surrogate decisions.

People might be required to appoint a surrogate decisionmaker for health and estate purposes when their tax status changes from employed to retired, and to document that appointment with the submission of their taxes (option 1). One disadvantage of this method lies in relying on, and further burdening, the country's tax collection system. It also does not account for individuals who become incompetent before they retire, those who do not retire, and those for whom emergency decisions must be made. The advantage is that more people would designate, and communicate their wishes to, a surrogate while still competent. People could be required to appoint a surrogate or surrogates every 10 years, through forms filed

with their taxes, voter registration, health insurance, or doctor. However, that approach excludes individuals who do not pay taxes, vote, or purchase health insurance. It also excludes those who never see a doctor or for whom emergency decisions must be made.

The disadvantages of option 2—giving tax credits or deductions—include the necessity for new tax laws, as well as the potential loss of tax revenue. Emergencies might also preclude the ability of a health care facility to find out the identity of the surrogate.

People claiming deductions for home or day care could be required to document that a surrogate has been identified (option 3). However, many individuals are already incompetent by the time they require tax-deductible care, so they would be unable to designate surrogates themselves. Other problems with option 3 include the increased burden on the tax review process, and the situation of people who do not have related caretakers,

Case managers might assist in or require the identification of a surrogate. If enrollment is not contingent on the identification of a surrogate (option 4) it might at least trigger the encouragement or counseling of the family on how to identify a surrogate. Again, however, by the time some assistance programs are used, many persons already are incompetent. Option 4 also increases the burden of reviewing eligibility for these programs.

The disadvantage of option 5 is that many board and care homes are unregulated. Also, health care facilities are not currently equipped to help identify surrogates.

Family consent provisions, creating an automatic surrogate decisionmaker for an incompetent individual are frequently tied to advance directives such as living wills and therefore may not be used until the individual is terminally ill. Under option 6, therefore, given the confusion over the definition of terminal illness, a family member may not be able to act as a surrogate until the last few days before an individual's death.

Option 7 would require States to tackle some possibly contentious issues head on, and legislators' decisions would likely be made without benefit of community consensus. The advantage of

this option is that, once powers were clearly determined, patients, families, surrogates, and administrators of health care facilities would have greater guidance in protecting the rights of an incompetent patient. Uniform guidelines for surrogate health care decisions could be adopted, making it easier for surrogates to act across State lines.

The advantage of option 8 is that treatment disputes could be circumvented, and surrogates with some evidence of what individuals would have wanted could carry out their wishes. However, surrogates, if appointed by the court or even by the individual, may not know the values and preferences of the individual.

Physicians and health care facilities not wishing to comply with the health care decisions of a surrogate could be compelled to refer the surrogate to alternate physicians or facilities that would comply. Surrogates could be given assistance in advocating an individual's wishes, and the occasionally combative situation when a physician disagrees about a surrogate's decision would be alleviated.

Surrogate decisionmakers area living extension of a person's right to self-determination. The greater awareness of surrogates—the need to appoint them, and the need to use them—has encouraged individuals to think about how they want to be medically treated. If people take the time to think about these issues and communicate their desires, not only is their own treatment course clearer, but society also gains by moving toward an informed consensus on how to treat persons with dementia.

Numerous methods are already in place for identifying surrogate decisionmakers. Existing methods are adequate; what appears inadequate is the use of those methods. Therefore, the challenge lies less in identifying surrogates than in stimulating and promoting their use.

The increasing number of elderly individuals with dementia makes the early identification and timely use of surrogates vital. However, steps must be taken to lessen the cost, ignorance, and fear associated with surrogate decisionmaking. Lawyers (and other individuals) formally assisting in

this process need sufficient, current information, as does the general public.

A number of these options might be used in concert, creating multiple opportunities for the early identification of a surrogate, and requiring—after a ^{grace} **period, and** with grandfather clauses—that individuals who have not complied seek a court order for treatment to be withheld or withdrawn.

ISSUE 4: Should the use of advance directives be stimulated?

Option 1: *Use advance directives solely as a guide to what treatment an individual would have wanted.*

Option 2: *Require people to execute advance directives when their tax status changes, or periodically.*

Option 3: *Introduce uniform State statutes on advance directives.*

Option 4: *Require attorneys who prepare advance health care directives to have specific training in this field.*

Option 5: *Permit nonlawyers who have received special training to prepare advance directives.*

Option 6: *Make compliance with advance directives mandatory, with punishment for failure to follow them.*

Under option 1, compliance with advance directives would not be mandatory, and the extent to which one would be followed would be determined by the aggressiveness of the physician or the family if the directive were disputed. That is basically the status quo. The main disadvantage of the status quo is the individual's uncertainty about whether his or her wishes will be respected. The advantage is that a societal consensus may continue to form in support of making compliance with advance directives mandatory.

Option 2, requiring people to prepare and sign advance directives, has the same advantages and disadvantages mentioned earlier with regard to identifying surrogate decisionmaking (issue 3, above). A percentage of people would not be reached through option 2.

States now have widely different statutes and interpretations. While option 3 might force States to legislate in advance of a clear-cut societal consensus, one advantage would be that advance directives executed in one State could be respected in another. Also, the public's participation in the legislative process leading to adoption of uniform statutes might go a long way toward the formation of a societal consensus.

Attorneys specifically trained to draft and execute advance directives (option 4) are likely to do so in a way that would be less open to subsequent medical, legal, or familial arguments. Again, a clarification of the decisionmaking powers of individuals appointed to carry out advance directives would be enormously helpful in knowing how to prepare such directives.

Additionally, advance directives could be prepared by other persons specifically educated in this field (option 5). Social workers, nurses, physicians, the staff of senior citizens centers, and others might be empowered to execute these directives after receiving appropriate education. While nonlawyers are not trained to craft legal documents, if living wills are viewed as a guide, as opposed to a mandate, then nonlegal personnel might be able, with training, to prepare them adequately. By allowing someone other than a lawyer to draft advance directives, they might become less daunting, more accessible, and less expensive for the average person.

One problem with option 6 is that many advance directives lack enough specificity regarding patient preferences and therefore are difficult to follow or maybe subject to a variety of interpretations. The advantage of making them mandatory is a greater likelihood that the autonomy of individuals would be respected after their own incompetence. The stress and anxiety of the dying process might be alleviated if individuals knew they would not be treated in a personally offensive way.

Physicians and health care facilities not wishing to comply with an individual's advance directive could be compelled to refer family members to alternate physicians or care facilities that would comply. They could also be required to assist family members in transferring patients with advance directives to those alternative caregivers. As noted,

many States and care facilities already have a policy on transfer, but do not follow it. Option 6 would give families assistance in carrying out a family member's instructions, and it would ease the occasional disagreement between physicians and families over adherence to an advance directive.

ISSUE 5: Should standard procedures for resolving disputes about treatment be adopted?

Option 1: *Use an Institutional Ethics Committee as a resolving body.*

Option 2: *Employ trained mediators to settle treatment disputes.*

Option 3: *Establish a standing body of physicians, nurses, social workers, ethicists, lawyers, laypeople, and others to act as an alternative to court resolution on a community or regional basis.*

Option 4: *Require health care facilities to assist the families in transferring the patient to a doctor or facility more sympathetic to their wishes in cases of unresolvable dispute.*

Option 5: *Require family members who disagree among themselves to sign documents releasing the facility and physician from liability.*

The advantage of option 1, reliance on an IEC, is that it creates an alternative arena in which cases might be decided without resort to the courts. IECs might allow family members and physicians who are unhappy with a treatment decision to air their concerns outside, rather than inside, a courtroom.

Mediators (option 2) could suggest alternate solutions that might be acceptable to both physician and family. Such mediators would need to be medically educated in order to understand the individual's prognosis, whether the physician has operated in the spirit of informed consent, and if all options had already been examined by physician and family. Operational and funding issues for this process would need to be worked out, but mediators offer the promise of resolving problems short of costly and time-consuming legal battles.

The disadvantages of option 3, as with the option of using such a group to determine patients' competence (issue 1, option 7, above), lie in the unknown composition and funding. Again, health care facilities, insurance companies, and other institutions might agree to fund and staff a group to resolve disputes, particularly as an alternative to court involvement. The advantages of such a standing body are the group's objectivity in arriving at alternate solutions, and its ability to recommend that certain cases go to the courts for resolution.

Option 4 will not help resolve disputes if no sympathetic alternative provider can be found or when the dispute is between family members, but it would allow many families and physicians to resolve their disputes peacefully.

Physicians and facilities may not want to raise the suggestion of a possible lawsuit, but a release from liability (option 5) might free the physician to suggest treatment based on medical decisions about the individual rather than on the physician's fear of a lawsuit. Clearer, more decisive, and bolder treatment decisions might result from a reemphasis on defensive medicine.

Treatment disputes sometimes arise between physicians and family members. Most of these disputes can be avoided. If a surrogate decisionmaker with clearly defined powers has been appointed in advance of an individual's incompetence, or if a clear directive has been executed, then many treatment disputes will be prevented. Until advance directives and surrogate decisionmaking powers are more clearly defined and widely used, however, methods to resolve treatment disputes are needed.

ISSUE 6: Should there be a distinction between unwanted treatment that sustains life and the unwanted cessation of such treatment?

Option 1: *Consider unwanted treatment that prolongs lifeless **objectionable than the unwanted cessation or withholding of treatment that would prolong life.***

Option 2: *Consider unwanted treatment that prolongs life just as **objectionable as the***

unwanted cessation of treatment that prolongs life.

Option 1 errs on the side of life-sustaining treatment. Yet unwanted prolongation of life may be seen as just as objectionable as the unwanted cessation of life-sustaining treatment.

Under option 2, physicians would be less inclined to practice defensive medicine, as they could be held liable for refusing to withdraw or withhold unwanted treatment.

Legal clarification of the status of unwanted treatment would be useful. As noted, once advance directive and surrogate decisionmaking powers are more clearly delineated, many existing sources of tension would be eradicated.

ISSUE 7: Should States include the decision to withhold or withdraw medical treatment in advance directives or in powers given to surrogate decision-makers?

Option 1: States could decide not to act, leaving resolution of disputes regarding the withholding and withdrawing of treatment up to the courts.

Option 2: Direct that critical health care decisions fall outside the purview of surrogate decisionmakers or advance directives.

Option 3: Grant surrogates and those following advance directives clear power to require the withholding or withdrawing of treatment.

Option 1, the current situation, has the disadvantages of forcing many more surrogates and family members through the trauma of court involvement, and of encouraging unwanted treatment of many individuals. The advantage of this option is that it allows States to await formation of a societal consensus.

The advantage of option 2 is that an extremely small percentage of incompetent individuals with unscrupulous surrogates would be protected. The disadvantages include the obliteration of individuals' right to determine critical health care treatment for themselves or to delegate that authority to a surrogate.

Granting surrogates and those following advance directives the power to withhold or withdraw treatment (option 3) might allow unscrupulous surrogates to make decisions only for their own motives, but it would also allow most individual preferences to be more easily respected, and might circumvent disputes between doctors, family members, and the patient.

Once again, a clarification of powers in the context of statutes on living wills, family consent, guardianship, conservatorship, durable powers of attorney, and durable powers of attorney for health care, is one of the best ways to stem the confusion and combativeness surrounding the issue of withholding or withdrawing life-sustaining treatment.

ISSUE 8: Should special precautions be taken when persons with a dementing illness are involved in biomedical research?

Option 1: Adopt the guidelines suggested in 1985 by the National Institute on Aging Task Force.

Option 2: Encourage the use of special informed consent forms or interview procedures when persons with dementia are involved in research.

Researchers and institutions receiving funding from the National Institutes of Health could be required to abide by the 10 provisions of the National Institute on Aging Task Force guidelines. Among other protections, option 1 would ensure that research protocols include a mechanism for designating a legally authorized surrogate decisionmaker when a patient-subject lacks decisionmaking capacity but does not object to participation in the research.

Forms for elderly persons should have short, clear sentences, large print, and simple explanations. Option 2 could entail having the forms critiqued by elderly consultants rather than by clinical researchers before they are given to the proposed patient-subjects. Researchers also could revise the traditional one-on-one, single interview process of obtaining an informed consent. Instead, they could leave a copy of the informed consent

form with potential subjects and let them study it at leisure and in the security of their own residences; encourage friends and relatives of the individual to be present during the interviews; use informational aids, such as tape recorders, slides, or sketches, to further explain the research; and cosign the form with the patient-subject as an affirmation that the research is an ethically invested and mutual service.

The enormous impact that dementing diseases have on individuals, families, and society prob-

ably justifies the continued use of incompetent persons as research subjects in attempts to find a cure or prevention. However, these vulnerable individuals must be protected from experimentation that is unsafe, unnecessary, or irrelevant. One approach is to encourage individuals to give their informed consent or refusal to research participation prior to becoming incompetent. As a study changes, surrogates should constantly re-evaluate whether an incompetent person would still wish to take part in the study.

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